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ALTERNATIVES TO INSTITUTIONALIZATION: AN EVALUATION OF STATE PRACTICES

Contract No. HCFA-500-77-0029

REVISED NEW YORK CASE STUDY

November 1978

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Submitted to

Department of Health, Education and Welfare
Health Care Financing Administration
330 C Street, S.W.
Washington, D.C. 20001

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INTRODUCTION

The Health Care Financing Administration (HCFA) has contracted with the National Institute for Advanced Studies (NIAS) to conduct a study of the development of alternatives to the institutionalization of the functionally disabled, including the developmentally disabled, the physically handicapped and/or chronically ill, the mentally ill and the elderly. The objectives of this study are to:

- reduce the inappropriate institutionalization of the functionally disabled
- facilitate the development of health and social services which prevent inappropriate institutionalization
- encourage states to utilize Medicaid programs which can help to support the goals of alternative care programs.

Four major tasks are identified as being the key activities involved in achieving the above objectives. These tasks include:

- conducting a literature search and the development of a methodology and analysis plan
- an on-site review of state practices
- an analysis of collected data preparation of a final report
- oral presentation of findings at a meeting of the Medicaid Management Institute.

The final product of this study will be a technical assistance procedural manual for use by state agencies (and other organizations and individuals) in the planning and establishment of appropriate alternatives to institutional care. This manual will be presented at the meeting of the Medicaid Management Institute.

This document is a case study of the State of New York. It details New York's current involvement in the development of alternative care programs. The descriptions herein are based upon personal interviews with various individuals and supporting materials obtained on-site.

OVERVIEW

The basic formula of New York state's deinstitutionalization efforts is the reallocation of responsibility for the care and maintenance of individuals from the state level to the local/ county level. The state maintains the role of financial agent and monitor of care through the establishment of standards for the delivery of services to deinstitutionalized persons. Within this historical context, the activities of the state agencies to be discussed can be best understood to be those of state agencies trying to transfer their direct service delivery capabilities to the local level while simultaneously developing the mechanisms necessary to promote and encourage the development of community based alternatives by local governments. The agencies in New York with prime responsibility for such activity are:

- the Department of Social Services
- the Department of Health
- the Department of Mental Hygiene

All of these agencies will be discussed in terms of their roles in deinstitutionalization and the development of community alternatives within the State of New York.

These agencies are discussed below in terms of their efforts to establish alternative care programs. For each of these programs, five key stages of development are discussed: 1) needs assessment, 2) program planning, 3) program development, 4) program operations, and 5) program evaluation. These individual stages are defined in detail in the Appendix of this report.

DEPARTMENT OF SOCIAL SERVICES

In an effort to support those disabled persons identified as being able to maintain themselves in a community setting, the Department of Social Services applied for monies to be used to fund a demonstration project designed to determine the feasibility of using a centralized unit to provide long term health care and related services in a cost effective manner. The result of this effort was the establishment of the Monroe County Long Term Care Program, Inc.

Monroe County Long Term Care Program*

The emphasis of the Monroe County Long Term Care Program is to maximize incentives for the non-institutionalization of the functionally disabled. This is achieved through the provision of these support activities:

- comprehensive pre-admission assessment
- in-depth patient and family counseling
- data collection via management information systems
- approve public payments and administer funds for long term care services

The program has a direct service delivery component, known as ACCESS. The goals of the ACCESS program include: 1) increasing the functionally disabled's choice of health services and places where these services can be delivered, 2) increasing support and services to the chronically ill and persons caring for them in their own homes, and 3) reducing the total costs of community long term health care services.

*Much of the information for this section of the report was obtained from the "Report to the Legislature on the Monroe County Long Term Care Program" 1977.

Needs Assessment

In 1974, 60% of the $75 million of Medicaid expenditures for Monroe County, New York went to long term care facilities such as nursing homes. Given that 10% of the county's population was over 65 years of age and that an estimated 20,000 required or would be requiring additional long term care, a number of persons (including institutional administrators, health and social services professionals, and Medicaid and Medicare officials) became concerned about this trend of long term care. The group presented its concerns to the Deputy Commissioner for Medicaid Assistance of the Department of Social Services and proposed the development of a program which was aimed to support and provide alternative long term care arrangements. The group used the above statistics to prove that a pool of potential consumers existed for such a program.

Program Planning

A grant application was developed and submitted by the Department of Social Services to the U.S. Department of Health, Education and Welfare in 1974 which proposed the establishment of a three year demonstration project. The proposal stated that the project would:

> Attempt to establish an effective community-based program designed to develop and coordinate alternatives and administer funds for long-term care for the elderly. In addition, various financing mechanisms, such as a fixed per capita aimed at encouraging local districts with state control for quality, to take an active posture to find or develop lower costs alternatives, may be utilized. The demonstration will take place in two settings with a third community used as a control. The organization, made up of "key" actors (e.g., DSS, Medical, Health providers and consumers), will supersede all other local governmental(Title XIX, Title XVIII, Social Services, Health, etc.), and (Blue Cross) current approaches and authority insofar as long-term care is concerned. An

> assessment of costs/benefits will be made to evaluate what effects have occurred to the patients and the system, and the program will also be evaluated with respect to accountability and quality of service.[1]

Funding for the project was approved in 1975.

Program Development

Early in the life of the project, its staff made contacts with representatives from regulatory, consumer, provider and third-party organizations. From this group, a steering committee of 25 members was formed to guide organizational and program development activities during the first year of operation. These activities included: 1) specifying organizational goals and objectives, 2) developing a constitution and a set of by-laws, 3) nominating, selecting and orienting board members, and 4) developing management policies and procedures.

During this stage, the experimental service delivery model of the project was also developed. It was decided that a patient assessment service called ACCESS, would be a major component of the project. This component was designed to provide comprehensive systems of assessment, counseling, placement, management and follow-up services to adults needing care arrangements. The goals of ACCESS were to:

- minimize inappropriate utilization of long term care facilities
- increase long term care options
- provide coordination and continuity of care management for clients needing long term care

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[1] "A Demonstration of Community-Wide Alternative Long Term Care Models," Proposal of New York State Department of Social Services to Social and Rehabilitation Service, DHEW, April 25, 1975. (Project Summary).

- simplifying existing procedures relating to assessment and utilization review
- collect information on needs, service utilization and placement.

All Medicaid eligibles in Monroe County were required to use ACCESS when seeking admission to long term care institutions. Medicare eligibles could be referred to ACCESS, and private pay clients could participate on a voluntary basis.

In order to introduce and promote ACCESS to the public at large, the staff of the demonstration project prepared an informational brochure, media presentations and held public speaking engagements.

Program Operations

The ACCESS program involves four operational stages: 1) intake, 2) assessment, 3) service plan development, and 4) follow-up. During the first stage a case manager obtains preliminary information from the potential client. The determination of admissions to the program is based upon this preliminary information. In the case of a positive determination, arrangements are made for a complete assessment. An assessment includes medical, nursing and psycho-social evaluations. An assessment of the clients home environment (in terms of geographic location, mobility of client in home, etc.) is made as well. A physician reviews the completed assessment and recommends a care plan. From this, a service plan is developed which presents a number of options. In consultation with the client and his/her family, an option is selected and the case manager assists in placing the client (placement assistance includes contacting providers and conducting and verifying service delivery). Once a client has been placed in a direct service program, ACCESS staff are responsible for monitoring client care through such areas as utilization review procedures and client contact.

Program Evaluation

A third-party evaluation will be conducted on the demonstration project and its experimental service delivery model (ACCESS). A contract has been awarded to an independent research firm. The evaluation design which has been developed addresses these four areas: 1) development efforts, 2) analysis of the ACCESS process, structure and functions, 3) ACCESS performance, and 4) effectiveness and impact studies. Because the ACCESS program did not become operational until approximately November 1977, the evaluation will not be completed until sufficient data on the program can be obtained.

DEPARTMENT OF HEALTH

The New York Department of Health is the co-administrator with the Department of Social Services of the State's Medicaid program. The Department of Health is responsible for the development of standards for licensure of facilities providing acute and long-term care, the administration of the utilization review program, and the administration of the medical assessment program for nursing homes. The Department of Health, through its licensure and standards development authority, sets forth guidelines for the development of neighborhood facilities. The development of too stringent guidelines and facilities construction requirements would result in a barrier to the development of community based services. Through its medical utilization review and medical audit responsibilities for certification of Medicaid payment, the Department determines the appropriateness of individual placement in state institutions.

The Department of Health is also the agency responsible for licensing and regulating hospital care facilities. Through the regulation and licensing of such facilities, the Health Department has played a significant role in fostering the development of community based services, especially through the use of Subchapter H of the State Hospital Code described below. Therefore, the Department of Health has the authority and responsibility to interface with the long-term care health system both at the institutional level, through its medical audit responsibilities, and at the community level, through its standards and licensing authority.

Subchapter H Program

The New York State Hospital Code modified the definition of a nursing home to include facilities providing nursing care to non-residents. The purpose of this amendment was to enable the operators of nursing homes and other health related facilities to deliver medical, preventive, diagnostic, therapeutic, rehabilitative or habilitative items or services by means of clinic visits, full-day care, evening care, night care or other care arrangements. In this way, long-term care providers are encouraged to develop a continuum of services designed to support persons in their own homes, and when this is inappropriate, to provide alternative settings. The Department of Health has used this vehicle to help implement adult day health care programs.

Needs Assessment

The Health Department developed a patient profile on individuals staying in long-term care facilities. This profile is entitled, "The Resident Patient Profile; A Comparison of Health Related Facility Residents and Nursing Home Patients in Mixed Long-Term Care Institutions in New York State." In part, this was an effort to obtain a better understanding of the characteristics of these residents so that programs being developed would more accurately reflect their needs and the services which should be provided by health related facilities.

Program Planning and Development

In using Subchapter H to implement adult day health care services, the Department of Health is attempting to answer the following questions:

- How many days of institutional care can a day care program prevent and at what cost savings?
- What measures of cost effectiveness can be obtained?
- How are the intangible benefits of keeping people out of institutions measured?
- How many persons can return to or continue in independent living as a result of adult day health care services and what would be the characteristics of such persons?
- How effective (how to measure) is the program in helping families care for the aged parent or spouse at home? To what extent have social or family strengths in the home been depleted? Can restoration or restitution of the person be accomplished to any meaningful degree?
- What services generate most use or what combination of services are most effective in reducing or eliminating institutionalization?
- How effective is coordination of community services by the facility (nursing home) and are there cost-savings in the use of community facilities and skilled manpower? 2

Program Operations

The Department of Health is responsible for reviewing applications to provide adult day health care services in nursing homes under Subchapter H. All applications are reviewed in terms of need, cost input, competence to deliver proposed services,

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[2]New York State Department of Health, Subchapter H - Guidelines and Procedures for the Implementation of Nursing Home and Health Related Services for Non-Occupants, July 1974, p. 2-3.

and past performance of the facility. Applications should include: 1) a program narrative, 2) provision for evaluation and assessment of client, 3) list and description of planned services, 4) use of personnel, 5) description of physical plant, 6) description of referral mechanism, 7) program cost profiles and 8) plans for periodic assessment of program.

Program Evaluation

Neither the Department of Health nor the Department of Social Services evaluated the effect of the Subchapter H Program in the development of adult day health care program in New York.

The Department of Mental Hygiene is comprised of three major divisions: the Division of Mental Health, the Division of Mental Retardation and the Division of Drug and Alcohol Abuse (only the activities of the Division of Mental Health are discussed below). The Department is responsible for the care and treatment of the state's chronically mentally ill persons.

The Division of Mental Health

The Division of Mental Health of the Department of Mental Hygiene has recently announced the initiation of phase one of its "five-year mental health plan." This plan is designed to ensure proper community placement and support services for the chronically mentally ill. The plan includes a reorganization of the delivery of existing institutional and community services.

Needs Assessment

Three types of needs assessments were performed which indicated the need for this five year plan:

- level of care needs survey of 27,000 patients in state psychiatric centers
- level of care needs survey of 2,000 former state inpatients
- analysis of indicators of health, mental health and social functioning in order to assess appropriate care settings. 3

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[3]New York State Department of Mental Hygiene, Division of Mental Health, Appropriate Immunity Placement and Support, Phase One Five Year Mental Health Plan, January 1978, p. 4-5.

These needs assessment activities began in 1975, well in advance of the finalization of the five year plan. They demonstrated that there is a need for a strengthened community support system for the chronically mentally ill.

Program Planning and Development

Aside from needs assessment, there were four other major components of the process used in developing the five-year plan. These components are: 1) the design of programs to address the identified needs, 2) the identification of existing programs, 3) the comparison of the existing programs with identified needs to define gaps in service and 4) the development of action plans to fill identified groups in service.[4] Because this strategy utilizes existing programs as opposed to creating new programs, the development of the five year plan necessitated a close working relationship with a number of other agencies. Together the agencies anticipated problems on implementing the plan (e.g., lack of transportation) and identified alternative actions.

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[4] Ibid., p. 13.

Program Operations

The community support system which is envisioned in the Division of Mental Health's five year plan includes the following principles:

- identify the population-at-large
- help disabled apply for income and other benefits
- provide crisis assistance
- provide psychosocial rehabilitation services
- provide other support services (e.g., living arrangements)
- provide medical and mental health care
- offer services to all those (family, friends, landlords, etc.) who come into contact with mentally disabled
- involve community in program planning
- establish grievance procedures and mechanisms to protect client rights. 5

Specific community programs which are identified include day treatment programs, functional maintenance programs, and sheltered workshops and transitional employment programs.

Program Evaluation

The five year mental health plan does not include provisions for program evaluation other than the screening of proprietary homes for adults to ensure that residents are properly placed.

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[5]Ibid, p. 19-21.

APPENDIX I

DEFINITION OF TERMS

Needs Assessment

A needs assessment is usually designed to answer one basic question: what services are needed by this population? In order to answer this basic question, strategies should be developed which outline a means of: (1) defining the characteristics of the potential client population; (2) determining which services are most needed (demanded); (3) determining to what extent the services already available address the needs presented; and (4) determining the extent to which available services are coordinated and accessible to clients.

Analyses such as the above will help to identify the current needs of the client population, i.e., significant gaps between the services and clients' need and the services the clients receive.

Program Planning

In planning the actual alternative care program, the results of the needs assessment are utilized in conceptualizing the specific features of the program. At this point in the process, questions usually asked include:

- What should the program ultimately achieve? In other words, what are its goals and objectives?

- How will the program be organized? Will it be independent, or subsumed within another unit?

- What resources are available to be used by the program? Are there advantages over using some as opposed to others?

- What categories of services, i.e., direct or indirect, will be offered by the program?

- Given the category(ies) of service, what specific ones will be offered by the program?

- What philosophies will be adopted in providing these services? Will staff be encouraged to emphasize advocacy, education, or both?

- What will be the characteristics of the staff employed?

- How will important decisions be made? Will all staff and clients be encouraged to participate in the process, or will the decisions only be made by the Program Director?

- Where will the program physically be located? What factors will influence its placement?

- Will all or only a segment of the functionally disabled population be served by the program? If only a segment, how is it decided which segment will receive the services?

Program Development

To ensure the services provided to clients are efficient, administrative procedures should be developed which define the manner in which supportive functions, such as recordkeeping, reimbursement procedures and coordinative mechanisms, are to be conducted. These functions are thought to be essential to the development of a program which positively impacts client status.

The final step in developing an alternative care program is the recruitment of clients. Such recruitment often involves an extensive effort to educate the potential client population in terms of the services offered and the requirements for receiving these services. This can be accomplished by canvassing the communities involved and using the media, special presentations, distribution of literature, etc., to advertise the new program.

Program Operations

Operating a service delivery program basically involves the performance of procedures designed to provide the services to clients in the most effective manner possible. These procedures ensure the client's successful movement through the service system, from the time of his/her entry to the time when the services are no longer needed. There are six such procedures: (1) initial client intake and screening; (2) client diagnosis/assessment; (3) service plan development; (4) case monitoring; (5) service termination; and (6) follow-up.

Initial client intake and screening describes what first takes place between the client and program staffer. During this interaction, the staff person must obtain vital information about the background of the client and the services which should be provided. The background information received will help the staff person ascertain if the potential client is actually eligible for the services needed. If not, avenues of recourse for the client can be identified.

If it is determined that the client is eligible for services, the staff person proceeds to more accurately assess the problems of the client and the extent of assistance needed. This assessment/diagnosis will culminate in the

development of a service plan, which specifies strategies for meeting the needs of the client. A service plan might also define time limits for the accomplishment of certain goals or objectives (e.g., the client will be relocated to better housing before winter).

Once the service plan is developed, it must then be implemented. During the course of implementation, the progress of the client will be monitored by the assigned staff person; any problems will be identified at this point and solutions proposed.

Assuming that any problems are eventually resolved, it is reasonable to expect the client to arrive at the point where he/she no longer needs the services that have been provided. Termination of services should only occur after consultation and counseling have taken place between the client and all service providers. If services are terminated, the client should be periodically contacted to determine how he/she is managing without the services.

Program Evaluation

Program staff and administrators need means of gauging how effective their program is in terms of meeting its specified goals and objectives. This can be accomplished by first identifying an evaluation model to be used in assessing the impact of the program. The next step is the collection of data which provide documentation on the program's efficiency, comprehensiveness, effectiveness, etc. (This information should include details about costs, client visits per month, average length of client visits, etc.) Following the collection of data, it should be analyzed according to an analysis plan (ideally, the analysis plan should be prepared before data

collection begins). Information resulting from the program evaluation will provide indicators as to what changes are needed.

The program discussed did not necessarily include each of these stages. Each program is unique in some respect. This case study has categorized the different approaches used in developing alternative services so as to facilitate the development of the technical assistance manual.